



The Evaluation of tide Across the Liverpool and Manchester City Regions

2018

tideTM
together in dementia everyday



This Report

This report evaluates the impact of tide's work funded through the Big Lottery Fund (BLF) from April 2017 to April 2018. The research for this evaluation was conducted by Arc Research and Consultancy.¹

This report covers the following:

Introduction



Context and Need



tide's Work



Impact



Conclusions



1. This is a summary of a longer report provided to tide, including methodology, literature review, network analysis and logic model. The longer report is available upon request.

Introduction to tide

tide is a UK wide involvement network of carers, former carers and health and care professionals who are working together to build a better future for carers of people living with dementia. Hosted by Life Story Network CIC, our team is made up of a group of former carers of people with dementia who are passionate about improving the lives of carers and those they care for across the UK. The network developed out of the Carers Call to Action, part of the Dementia Action Alliance.



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It is as much about the connection with people that understand the things you are going through. Everyone seems to support each other which is nice because sometimes you feel so alone with this journey and illness.

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“

They've given me back my confidence through the tools and the skills to manage my emotions.

”

Context and Need

The Prime Minister's 2020 Challenge on Dementia in 2015 and the Care Act 2014 changed the landscape in which carers of people living with dementia lived. The PM's Challenge set out to make England the *'the best country in the world for dementia care and support and for people with dementia, their carers and families to live.'* The Care Act (2014) for the first time assured the rights of a carer to an assessment of need alongside that of the person they care for, making *'integration, co-operation and partnership a legal requirement on all agencies involved in public care, including the NHS.'*

This suggests a policy context in which the needs of carers are considered and engagement is at the fore. However, the evidence on the implementation of policy suggests that opportunities to give equal weight to the needs of carers are being missed, along with a failure to engage carers in developing services.

Following on from the PM's Challenge, in 2016/17 tide worked with the Alzheimer's Society, and partners, to develop the Dementia Statements. Based on the Equality Act, the International Human Rights Act, the UN Convention on the Rights of Persons with Disabilities, Health and Care Legislation and Mental Capacity Legislation, the Statements set out what is essential to improve the lives of people living with dementia and their carers.

tide's Big Lottery Funded work is located as part of this wider stream of thinking related to developing a rights-based approach to dementia and carer support. Herein, the particular needs of carers of people with dementia would be acknowledged, and their rights accounted for in policy and practice. Moreover, carers themselves would be engaged and involved in making this change using their knowledge and skills as experts by experience who are able to challenge professionals and make change happen.

tide's Work

We're determined to change the way carers are recognised, valued and treated. We believe that services and support for carers of people with dementia are a fundamental and necessary human right. It is our mission to ensure that the needs of these carers are recognised and valued by absolutely everyone in the UK: politicians, the health and social care system, the educational system, employers, the media and the general population.

Our activities include:



Equipping carers with the skills needed to use their caring experience to influence positive change, through our Carers Development Programme.



Influencing government, legislation, policy and programme design and delivery, by making sure carers have a 'seat at the table' as an expert by experience.



Campaigning for better support for carers of people with dementia and challenging the perceptions of carers in society.



Educating people, organisations and the public on the important role that carers of people with dementia perform.



Connecting carers of people with dementia with each other, to form a UK wide network of carers.

Impact

Outcome One - Current and former carers gained confidence and new skills that increased their ability to influence positive changes in policy, commissioning and services.

Carers reported changes to capability and skills; in particular the skills and capability to manage their own emotions while attempting to influence others.

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At the point I attended the Maze Runner course I was just plain livid, I was just so angry with everything and everybody. Maze Runner gave me so much information that it immediately calmed all of that down. tide has given me a much clearer focus, if I'm not getting anywhere with somebody I can then come back with some very clear information and legal grounds for them actually having to seriously consider what we have to say.

”

Carers have spent time influencing the understanding of professionals at conferences and congresses, have contributed to research and have taken part in national policy debates. Carers have taken action on a range of issues such as advanced care planning, end of life care, dementia care in hospitals, the Dementia Statements, dementia rights and developing outcome measures for people living with dementia.

“
I was approached at the end by a few professional people saying it was so impacting and I was told that I ended my little talk by saying 'you are professionals but with our loved ones we are the experts' and this made a big impact and made people think.

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Outcome Two - Carers of people with dementia report feeling less isolated and their health and wellbeing improved as a result of peer connections/support through this project.

Positive changes were identified for the following effects of carer interaction with tide:

Wellbeing has improved through contacts with other carers

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I feel relieved that I'm not alone on my journey and there is support for me

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Isolation has reduced through improved connections with others

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I've got a group of people through tide that I know I can ask “look this is happening, who do I go to?”.

”



Sense of positivity and control within their environment has improved

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I feel very proud to be a part of tide. The big one for me was Dementia Congress in November in Doncaster, that had an immense impact on my journey with dementia in a very positive way

”



Outcome Three - Development of policies, research, education, commissioning and services are more responsive to carers' needs by establishing the voice of carers

There is evidence of impact varies across the different types of organisation (policies, research, education, commissioning and services) and the level at which they work (local, regional and national).

 tide have a seat at a number of policy and advisory forums including:

- Public Health England Dementia Governance Board
- Task Force for Dementia Friendly Hospitals Programme (Dementia Action Alliance)
- Dementia Expert Reference Group National Collaborating Centre for Mental Health
- National Dementia Action Alliance Steering Group
- Royal College of Nursing - Nursing Advisory Group
- Department of Health Citizens Engagement Programme

 Research organisations are starting to engage tide carers early in the bid writing period. This has allowed carers to influence the shaping of the work and co-design the research. tide carers are working with several universities including Liverpool, Leeds Beckett and SPRU on research projects. tide have also been approached by national research organisations the National Institute for Health Research and the national organisation Join Dementia Research to develop an explicit partnership to support their research work.

 tide have engaged with the STPs in Liverpool City Region, Manchester City Region and Yorkshire and Humber. There is a fit between tide's ethos and the values on engagement enshrined in the STPs.

 Direct impact has been witnessed by carers' active participation in the UK Dementia Congress – both in workstreams and in the development and delivery of the plenary End of Life session; in national practice and policy workshops including on Advanced Care Planning with NHS England; and in professional conferences.

Conclusions

- ➔ tide's Big Lottery Funded activity has generated improved confidence and new skills for carers' and former carers'.
- ➔ tide input generates improvements among carers' and former carers' well being; reduces isolation; and, generates improvements in carers' positivity and sense of control within their environment.
- ➔ Opportunities have been identified and grasped for carers' and former carers' to influence at national level and at City Region level. These opportunities have demonstrated the confident and effective use of carers' new influencing skills.
- ➔ There have been notable successes with good progress being made at City Regional and National level, with positive and demonstrable impact.







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